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## ABSTRACT

Attitudes concerning the Human Genome Project were reported by faculty (N=40) and students (N=66) from a liberal arts college. Positive attitudes toward the project involved privacy, insurance and health, economic purposes, reproductive purposes, genetic counseling, religion and overall opinions. Negative attitudes were expressed regarding discrimination and judicial purposes. Faculty ranked such factors as genetic disease within a family, reproductive purposes, interest in arts, interest in humanities, genetic-related counseling, and privacy for genetic information higher than the students did. Differences between male and female were shown with regard to number of children, genetic disease in the family, and the use of genetic knowledge for reproductive purposes. (Contains 19 references.) (Author/DDR)

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Running head: THE HUMAN GENOME PROJECT

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Attitudes Towards The Human Genome Project

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### Abstract

Attitudes concerning the Human Genome Project were reported by faculty (N=40) and students (N=66) from a liberal arts college. Positive attitudes toward the project involved privacy, insurance & health, economic purposes, reproductive purposes, genetic counseling, religion, and overall opinions. However, negative attitudes were expressed regarding discrimination and judicial purposes. Faculty ranked higher such factors as genetic disease in the person's family, reproductive purposes, interest in arts, interest in humanities, genetic-related counseling, and privacy for genetic information than students. Differences between male and female were shown with regard to number of children, genetic disease in the family, and the use of genetic knowledge for reproductive purposes.

Key words: attitudes, human genome project, genetic counseling, health and insurance.

### Attitudes Towards The Human Genome Project

There is considerable controversy associated with the possible ramifications of the Human Genome Project. With recent media coverage, the general public has gained more knowledge about the project. Fears, as well as excitement, have been expressed about its future implications. Little research has been implemented to find those general attitudes the public has toward the project. With the research and scientific advancements of the project increasing at an ever accelerating pace, this study is an effort to gain information on the early attitudes the public has about the project.

Although the Human Genome Project is a recent phenomenon, several past discoveries have led to the basic research for the project. In 1953, James Watson and Francis Crick made a great scientific breakthrough by succeeding in constructing the molecular model of DNA. This model, known as the Watson-Crick model, described the helical arrangement of base-paired strands of DNA. This discovery, as well as breaking the genetic code by determining how proteins are synthesized in the cell, led to the research of the Human Genome Project (Watson, 1981).

The Human Genome Project's three main goals are to establish a genetic map of markers along each of the 24 chromosomes, to make a detailed map of DNA, and to sequence the 3 billion nucleotides that constitute the human genome (Murray, 1994). This would involve knowledge of human genetic make-up, including genes for predisposing some diseases and personality traits. Many believe the project will find cures for diseases which today are incurable. Proposed in 1988, the Human Genome Project costs approximately 200 million dollars per year in the United States

alone, and will be completed by the year 2005, with an estimated cost of about \$1 billion (Olson, 1995).

Francis Collins, director of the National Center for Human Genome Research, states, "...Not doing this is unthinkable. It contains within it the seeds of alleviation of all our suffering. It would be unethical to delay" (Appleyard, 1996, p.14) However, a surprisingly common attitude is that a person may not want to know if they are predisposed for a disease, especially when there is no cure available. Bryan Appleyard states, "A sufferer from muscular dystrophy might rejoice to hear the gene that has caused his disease has been found, only to have his hopes dashed when he realizes nothing can be done to cure him" (1996, p.17) This is an issue with no real answer at present.

A similar issue is of privacy of genetic information. Some argue that the government should make the decision that all people be genetically tested. The United States has previously created two mandatory laws forcing people to be genetically tested. The first was a mandatory sterilization law to prevent mentally retarded people from reproducing and the second was for genetic screening of sickle cell anemia. These laws have since been repealed due to the argument that the government should not intrude on personal decisions (Murphy, 1994). If the government should not intrude on such personal decisions, is it right to make all people undergo genetic testing? The September, 1995, issue of Nature stated, "A consensus is emerging that the genetic information should be confidential to individuals and their physicians" (p.262). Hopefully, a doctor's ability to help the patient is increased by knowing his/her genetic composition. Insurance companies have a strong interest in knowing the risks of their policy holders by obtaining their genetic backgrounds (Warren, 1995). Many people fear insurance companies may

"drop" or change the premiums of policy holders on the basis of new genetic knowledge. Paul Billings' research on genetic discrimination stated, "Genetic discrimination exists and is manifested in many social institutions, especially in the health and insurance industries" (1992, p.476). This is a crucial and as yet, unsettled issue.

The Human Genome Project also raised the issue of discrimination in the justice system. Researchers have found that there is a link between genes and behavior (Bouchard, 1994). One controversial implication is that there are "born" criminals who's genetic make-up controls their behavior (Mann, 1994). With this in mind, judges may sentence someone differently if they knew their genetic disposition was that of abnormal violence. The Human Genome Project not only could provide information about personality, but a person's DNA could also be used as raw evidence in court. New genetic technology could imply that closed cases be opened to free possible wrongly-convicted persons in jail (Murphy, 1994).

Along with the alterations in the justice system, new changes in our economy are also foreseen. Bioinformatics, which is the term used for the computer technology essential in the advancements of the project, is a new emerging field. New software, training programs, and computer technologies are needed to meet the demands of the project and utilize its findings. In addition, pharmaceutical companies are realizing the value of the project and are funding to smaller companies and bioinformatic advisory boards (Gershon, 1995). Genetic counseling, which deals with the human problems of a genetic disorder, requires trained persons to communicate disorders to individuals or families (American Journal on Human Genetics, 1975). Other psychologists will be needed to help with the social issues as well. The opportunities are endless surrounding the possible economic advantages of the project.

Other options, though controversial, are those concerning the use of the Human Genome Project to make procreative decisions. For example, a person may want to know the genetic composition of their potential mate before getting married. Couples may choose to not have children because they carry genes for a specific life threatening disease. Today's reproductive genetic technology provides many opportunities for pregnant women and their families to obtain direct information about the genetic makeup of the developing fetus (Davis, 1993). The Human Genome Project takes this information a step further by providing knowledge that could alter the genetic make-up by adding or taking away particular genes of a fetus. Attaining this knowledge could be the basis for creating a genetic underclass because wealthier people may choose to alter the fetus to get the "best" genes or adding genes to make a "perfect" baby (Murphy, 1994). By altering a fetus genetic composition, a genetic underclass could be developed with individuals who do not have the financial capability to use genetic technology. Although all persons carry the genetic material to some diseases, people in financial difficulty may be discriminated against due to lack of money for altering their genetic compositions to "healthier" ones. Nature states, "Fears abound that genetic information will be used unfairly to discriminate against members of a population who are already cruelly disadvantaged by their genetic constitutions" (1995, p.273). Some worry the project will go to the extreme of creating a demographic imbalance in the human population which will give no value to individual differences. It is foreseen that strict guidelines are imperative to the progression of the project, or the societal implications will be detrimentally overwhelming. In 1993, Fetal Diagnosis Therapies boldly claimed, "[There is] a social underclass based on genetic discrimination existing, and future genetic testing or screening programs need review by medical scientific, legal, and social policy experts, as well as the public,

and may require modification" (p.472).

Another discrimination issue involves using genetic information to classify a person as belonging to a particular group. For example, a person may belong socially to a certain group, but not be genetically the same as the peers within the group. The genetic difference would then infringe on the social aspects of a person's life. Instead of merit, if information is made available, people may be discriminated against in applying for jobs, examining professions, electing political figures, etc. may all be utilized to access a person's capability.

The psychological effects of the project are unknown to both scientists and psychiatrists. How will knowing you are predisposed for a disease with no available remedy affect your quality of life? Knowing that one has a strong chance of getting a disease may positively effect their lives. Gina Fisher, a court reporter, recently stated in Parade Magazine, "Without it [genetic testing] , I would have waited months before being examined. My doctor found a lump, and [after further tests] I had both breast removed"(p.9). Disease precautions and preventative health care measures may become a lifestyle in order to lessen the onset of disease. The opposite effect could happen though. A person may feel that they have no hope of being a healthy individual because they are predestined from birth for a disease. Is there a way that we can prepare the world for the knowledge which may change their outlook on life forever? As earlier mentioned, genetic counseling attempts to help the individual comprehend the medical facts of their heredity, understand alternatives, and choose a course of action which would help them adjust to the disorder (American Journal of Genetics, 1976). However, genetic counseling only helps the individual with the initial coping processes. The lifelong effects of the change will become a part of not only the individual, but the family members as well.

Some people wish to stop the Human Genome Project because they feel it is unethical. Ethics are discussed particularly when reflecting on the religious aspects of the project. Many Christians view their genetic knowledge as property of God. In an interview with Dr. Richard Land, executive director of the Christian Life Commission of the Southern Baptist Convention, he states, "We see altering life forms, creating new life forms as a revolt against God's sovereignty, an attempt by mankind to usurp God and be God." An opposing view from James Watson states that "when faced with the ravages of disease, there is also the immorality of doing nothing" (Appleyard, 1996, p.15). Scientists explain that the goals of the project are admirable by curing disease to alleviate the undue pain and suffering of individuals. Some feel that the project is in God's plan for us and that the choices present to us are a part of the next phase of humanity. Collins states, "It's God's plan and in the tradition of medicine. Christ was a healer" (Appleyard, 1996, p.14).

Genetic information is currently used by providing parents with a choice of abortion in the case of a handicapped fetus, by providing DNA knowledge in order to manufacture more precise drugs, and in gene therapy, which is the manipulation of an individual's genome to correct malfunctions (Appleyard, 1996). The new genetic knowledge gained through the project will have great effects on the quality of medicine and technological advances within our lifetime. Scientists will very likely be able to predict which individuals are predisposed to disease. This knowledge will change the way we view ourselves and the people around us. This project raises many issues relating to privacy, health care, discrimination, and religion. Many questions must be answered about the social, ethical, and legal implications of the project.

This study examined the attitudes of the faculty and students at a small liberal arts college. In addition, differences in the attitudes of males and females were analyzed. Attitude is defined as "a feeling or emotion towards a fact or state" (Mish, 199, p. 114). The attitude questionnaire includes a general definitional discussion of the Human Genome Project, and asks for respondents' opinions about issues based on the current literature regarding the project.

### Methods

#### Participants & Procedures

Participants were faculty and students from a liberal arts college with 1100 students and 78 (full time) faculty members. Questionnaires were distributed anonymously on April 3, 1996 to faculty via campus mail. Forty questionnaires were completed and returned. Sixty-six undergraduate students completed the questionnaires on April 13, 1996 in groups of 10-20. Some students were given partial credit in general psychology classes for participation.

#### Materials and Design

The materials were comprised of three main parts: a one page general definitional discussion of the Human Genome Project, a fifteen question demographics sheet, and the Human Genome Project Questionnaire (HGPQ). The Human Genome Project general definitional discussion is as follows:

The Human Genome Project is an international collaboration of scientific research efforts to characterize the form and content of the Human genome (the hereditary instructions that guide the development of a human being). The three goals of the Human Genome Project are to establish a genetic map of markers along each of the 24 chromosomes, make a detailed map of DNA, and to sequence the 3 billion nucleotides that

constitute the human genome. Proposed in 1988, the Human Genome Project cost \$200 million dollars per year, and will be completed by the year 2005, with an estimated cost of over \$1 billion.

The new genetic knowledge gained through the project will have great effects on the quality of medicine and technological advances within our lifetime. New drugs and therapies may be developed to utilize this genetic information. Scientists will very likely be able to predict which individuals are predisposed to disease. This knowledge will change the way we view ourselves and the people around us. This project raises many issues relating to privacy, health care, discrimination, and religion. Many questions must be answered about the social, ethical, and legal implications of the project. What are your attitudes concerning the Human Genome Project?

The demographics sheet contained questions such as sex, age, profession, hometown population, general interests, scientific background, knowledge about the Human Genome Project, and knowledge of genetic disease in family. HGPQ was compiled as a series of 44 statements which requiring Likert evaluations. These were organized into nine sections containing related statements as follows:

1. Statements 1-4 expressed general attitudes toward the project (e.g. "The Human Genome Project is a beneficial program which should be explored.") For this section, the highest score of 28 denoted a general attitude in favor of the project.
2. Statements 5-19 addressed the issue of privacy (e.g. "Genetic records should be used only upon permission of the individual.") For this section, the highest score of 63 denotes an attitude in favor of privacy of genetic information.

3. Statements 14-17 contained insurance and health statements (e.g. "If all my genes were known I would fear that my insurance company would drop me.") For this section, the highest score of twenty eight denotes a strong attitude toward the issue of insurance and health.

4. Statements 18-20 dealt with using genetic information for judicial purposes (e.g. "If one is found, a gene for aggression should prevent a person from being prosecuted for criminal behavior." For this section, the highest score of 21 denotes a an attitude in favor of using the genetic information for judicial purposes.

5. Statements 21-26 were about using the genetic information to benefit the economy (e.g. "Private industries should be able to profit on endeavors based on discoveries made in institutions that are supported by the public.") For this section, the highest score 42 denotes in attitude in favor of using the information to benefit the economy.

6. Statements 27-30 pertained to using the information for reproductive purposes (e.g. "I would want to know my unborn child were predisposed for any diseases.") For this section, the highest score of 28 denotes an attitude in favor of using the information for reproductive purposes.

7. Statements 31-40 regarded issues of discrimination (e.g. "Health care should screen populations if it is for the future benefit of the population.") For this section, the highest score of 70 denotes a strong attitude regarding issues in favor of using genetic information for social issues.

8. Statement 41 referred to genetic-related counseling (e.g. "People taking genetic tests should be counseled about the possible threat to self image and sense of personal identity the testing may impose.") For this section, the highest score of 7 denotes an attitude in favor of

genetic counseling.

9. Statements 42-44 addressed the issues of religious beliefs guiding an opinion of the project (e.g. "My religious beliefs guide my thinking regarding the Human Genome Project.") For this section, the highest score of 21 denotes an attitude highly influenced by religious beliefs. Item 45 asked for any additional open-ended statements about the Human Genome Project.

The data were analyzed using the above categories and demographic information to first describe the general attitudes, then to show which factors account for a person's general attitude. Discriminant analyses were performed to determine differences between faculty and students and between males and females.

### Results

The means scores, calculated for the nine categories, are summarized in figure 1.

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Insert Figure 1 here.

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Our participants most strongly favored the right to privacy of genetic information.

### Regression Analysis of General Factors

A regression analysis was calculated to determine which factors account for our participants' general attitude toward the Human Genome Project. The analysis used general attitude as the dependent variable with all other categories as factors. The predictors of general attitudes toward the project are summarized in Table 1. The most important determinants were basic

The second discriminant analysis used male and female groups as dependent variables with the nine questionnaire categories as factors. The significant factors were student/faculty group (Wilks' Lambda=.88,  $F=15.03$ ,  $p<.0002$ ; male  $M=1.62$ , female  $M=1.27$ ), number of children (Wilks' Lambda=.90,  $F=11.39$ ,  $p<.001$ ; male  $M=1.28$ , female  $M=.52$ ), genetic disease in family (Wilks' Lambda=.94,  $F=6.52$ ,  $p<.01$ ; male  $M=1.68$ , female  $M=1.44$ ), using genetic knowledge for reproductive purposes (Wilks' Lambda=.96,  $F=4.44$ ,  $p<.04$ ; male  $M=19.10$ , female  $M=16.49$ ). The overall model was significant (Eigenvalue=.55, Wilks' Lambda=.65, Chi sq.=41.02,  $df=26$ ,  $p<.03$ ), with 74.31% of participants correctly classified.

### Discussion

Attitudes toward the Human Genome Project are generally positive. Only those statements regarding discrimination and the use of genetic knowledge for judicial purposes showed negative attitudes. Those factors that account for general attitudes relate to how much a person knows about the Human Genome Project, the use of genetic information for reproductive purposes, genetic-related counseling, and hometown population. It would appear that as one becomes more educated about the project the attitude of the project is increased. Additionally, there are several prenatal screenings presently available and the technology is being utilized to make procreative decisions. It would seem logical that continuing to employ procreative information would be a factor in attitude toward the project.

Our results have shown several significant differences between faculty and students and between males and females. Since the demographics of our student and faculty groups were similar in nature, it seems reasonable to conclude that the differences found between these groups

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Insert Table 1 here.

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knowledge of the project, using genetic information for reproductive decisions, and use of genetic counseling.

#### Discriminant Analysis of Faculty & Student Attitudes

This discriminant analysis, which proved to be highly significant, used student and faculty groups as the dependent variables with the nine categories as factors. The factors which attained significance were number of children (Wilks' Lambda=.57,  $F=81.53$ ,  $p<.0000$ ; student  $M=.18$ , faculty  $M=1.79$ ), gender (Wilks' Lambda=.88,  $F=15.03$ ,  $p<.0002$ ; student  $M=1.79$ , faculty  $M=1.34$ ), genetic disease in family (Wilks' Lambda=.88,  $F=13.98$ ,  $p<.0003$ ; student  $M=1.43$ , faculty  $M=1.74$ ), using genetic knowledge for reproductive purposes (Wilks' Lambda=.89,  $F=12.74$ ,  $p<.0005$ ; student  $M=3.43$ , faculty  $M=3.19$ ), interest in arts (Wilks' Lambda=.91,  $F=10.83$ ,  $p<.001$ ; student  $M=4.34$ , faculty  $M=5.49$ ), interest in humanities (Wilks' Lambda=.93,  $F=7.92$ ,  $p<.006$ ; student  $M=5.10$ , faculty  $M=5.96$ ), use of genetic counseling (Wilks' Lambda=.95,  $F=5.76$ ,  $p<.018$ ; student  $M=14.39$ , student  $M=14.00$ ), and privacy of genetic information (Wilks' Lambda=.95,  $F=5.33$ ,  $p<.022$ ; student  $M=43.92$ , faculty  $M=46.92$ ). The overall model was found to be highly significant (Eigenvalue=6.49, Wilks' Lambda=.13,  $\text{Chi Sq}=189.32$ ,  $\text{df}=26$ ,  $p<.00$ ). The percentage of participants correctly classified by group was 98.17 %.

#### Discriminant Analysis of Male & Female Attitudes

in attitudes toward the HGP result from education level, age, and life experiences. The faculty and students participating in our study were primarily white, middle class persons with health care of some kind. Additionally, there is a higher percentage of males in the faculty than in the student body. Students are more willing than faculty to use genetic knowledge for reproductive purposes and to engage in genetic counseling. Faculty on the other hand, are more likely to know of genetic diseases in the family, wish to keep genetic information private. They also hold stronger interest in the arts and humanities.

Males were more likely than females to know of genetic diseases in their families and to use genetic information for reproductive purposes. It is interesting, given these two differences, that men and women did not differ in favoring the use of genetic-related counseling. Perhaps women feel the need for more support.

Our student/faculty differences suggest that as people become more knowledgeable about the project, their attitudes will change. The issue of genetic disease and privacy, it seems, will become more salient as the rapid unfolding of what the Human Genome Project will mean for society continues.

### References

- Appleyard, Bryan. (1996, March 10). We've cloned sheep, we can do the same with humans. We're ready to put pig organs in a heart patient. But just how far do we go...Unpicking the Fabric of Life. The Sunday Times, pp.14-16.
- Billings, Paul R. (1992). Discrimination as a Consequence of Genetic Testing. American Journal of Human Genetics, pp.476-482.
- Bouchard, Thomas J. (1994). Genes, Environment, and Personality. Science, pp.1700-1701.
- Brandt, Kerry A. (1993). The GDB Human Genome Data Base: a source of integrated genetic mapping and disease data. Bulletin of Medical Library Association, pp.285-292.
- Charo, Alta R. (1993). Effect of the Human Genome Initiative on Women's Rights and Reproductive Decisions. Fetal Diagnosis Therapies, pp.148-159.
- Davis, Jessica G. (1993). Reproductive Technologies for Prenatal Diagnosis. Fetal Diagnostics Therapies, pp. 28-38.
- Genetic Counseling. (1975). American Journal of Genetics, pp.240-242.
- Georgetown College Catalog. (1995) Georgetown: Georgetown College.
- Gershon, Diane. (1995). The boom in bioinformatics. Nature, pp.262.
- Holtzman, Neil A. (1994). Discovery, transfer, and diffusion of technologies for the detection of genetic disorders. International Journal of Technology Assessment in Health Care, pp.562-572.
- Kelves, Daniel J. and Hood, Leroy. (1992). The Code of Codes. Cambridge: Havard

University Press.

Mann, Charles C., (1994). Behavioral Genetics in Transition. Genes and Behavior, pp.1686-1689.

Mish, Frederick, M. (1991). Webster's Ninth New Collegiate Dictionary. Massachusetts: Merriam-Webster Inc.

Murphy, Timothy F. (1994). Justice and the Human Genome Project. Berkley: University California Press.

Olson, Maynard. (1995). A time to sequence. Science, pp.394-396.

Ubell, Earl, (1997, January 12). Should You Consider Gene Testing? Parade Magazine, pp.8-9.

Warren, Jim. (1995, December 15). Discrimination: dark side of gene testing. Courier Journal, p.A9.

Watson, James D. (1980). The DNA Story. San Francisco: W.H. Freeman & Co.

When is genetic screening permissible? (1995). Nature, p. 273.

Table 1

Regression analysis with general attitude as dependent variable with all factors.

| <u>Variable</u>                                      | <u>beta</u> | <u>p&lt;</u> |
|------------------------------------------------------|-------------|--------------|
| Human Genome Project Knowledge                       | .29         | .0008        |
| Using Genetic Knowledge for<br>Reproductive Purposes | .30         | .0006        |
| Use of Genetic Counseling                            | .26         | .003         |
| Hometown Population                                  | .18         | .03          |

Figure Caption

Figure 1. Mean scores for the nine categories HGPQ.

